



ALERT

News from the UFMCC on AIDS Legislation, Education, Research and Treatment.

NEW UFMCC POLICY

The UFMCC General Council adopted a recommended "Policy on Disabilities and/or Life Threatening Illnesses" at their March, 1989 meeting in Los Angeles, CA. Following a presentation by Dr. Alan Emery, co-author of Managing AIDS in the Workplace, and the Rev. Jim Mitulski, Pastor of MCC San Francisco, the Council refined, revised, and approved the proposed policy, submitted by MCC San Francisco.

The following policy will be included with the General Council Report to the UFMCC General Conference, in July, 1989, for adoption as recommended policy.

POLICY ON DISABILITIES AND/OR LIFE THREATENING ILLNESSES

The AIDS epidemic brings to our awareness the reality of disabilities and/or life threatening illnesses and their impact on all people. We believe that all people with disabilities and/or life threatening illnesses are to be treated with respect and compassion.

The UFMCC expresses its commitment to people with disabilities and/or life threatening illnesses through the following policy for employees of the UFMCC. For the purposes of this policy the UFMCC shall include Fellowship, District and local levels.

(1) Employees who are affected by a disability and/or life threatening illness will be treated with compassion and understanding in their personal crisis. Reasonable efforts will be made to accomodate seriously ill employees by providing flexible work areas, hours and assignments whenever possible or appropriate.

(2) Employees with any disability and/or life threatening illness have the right to continue working so long as they are able to continue to perform their job satisfactorily and so long as the best available medical evidence indicates that their continual employment does not present a health or safety threat to themselves or others.

(3) In the case of an employee with a disability and/or life threatening illness, confidentiality of employee medical records will be maintained in accordance with existing legal, medical, ethical and management practices.

EDITOR: Rev. Steve Pieters

MAY, 1989

(4) In regard to the life threatening disease of AIDS and it's related conditions, a person carrying the HIV virus is not a threat to co-workers since HIV infection and disease is not spread by common everyday contact. For this reason the HIV status of an employee is not relevant information in regard to the health and safety of his/her co-workers. Therefore, the HIV antibody or HIV virus test will not be used as a prerequisite for employment or a condition for continued employment. Knowledge or presumed knowledge of HIV antibody and/or HIV virus status will not be used to discriminate against an employee for any reason.

(5) The UFMCC and its employees will be sensitive to the needs of critically ill or disabled colleagues, and to recognize that continual employment for an employee with a disability and/or life threatening illness is often life sustaining and can be both physically and mentally beneficial.

(6) The UFMCC will develop, as necessary, educational programs and community service referrals for employees with disabilities and/or life threatening illness.

(7) The UFMCC shall be responsible for assuring, wherever possible and applicable, that all of its employees have adequate medical/health insurance and disability insurance.

CONCLUSION: This policy reflects the UFMCC's commitment to act as a prophetic ministry of peace and social justice, promoting the nurturance and growth of our members and our active involvement in the society around us.

ROCHESTER INTERFAITH VIGIL GROWS

The weekend began Friday, February 3rd when people of many faiths gathered together to worship and share in a time of healing. During the service, a husband and wife spoke about their experience with AIDS. Addicted to intravenous drugs, the husband went "straight" five years ago and married three years ago. Two and one-half years ago he fell ill and discovered he had AIDS. He later found that the virus had been passed on to his new wife.

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Rochester Interfaith Vigil (Cont'd)

Representatives from seventeen faith groups, Quaker to Catholic, Presbyterian to Zen, Jewish to Methodist, Baptist to Spiritualist, Hispanic Pentecostal to MCC took part in the 24 hour vigil which began after the Friday service. At 9:00 am Saturday the vigil participants processed from St. Mary's Catholic Church (site of the opening service and initial vigil hours) across the downtown square to the site of the final service. The interfaith services culminated at the First Universalist Church on Saturday, February 4th with the speaking of names of loved ones lost to AIDS. The pastor of St. Mary's church of the Deaf delivered a short homily in sign language which was translated for the hearing. He spoke of how remembering those who have died of AIDS reminds us that lives are valuable and that the time is too short to waste without honest communication about AIDS.

"I have been very moved by the tremendous response of so many faith communities to the Vigil," said the Rev. Cathy Elliott, pastor of Open Arms MCC. AIDS Rochester, Inc. and Open Arms MCC are co-sponsors of the annual services and prayer vigil.

PRESERVING YOUR MEDICAL AND DISABILITY BENEFITS

*By John S. James
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AIDS TREATMENT NEWS, Issue 76)*

Many persons with serious illnesses lose insurance and medical benefits to which they are entitled, because of the complex rules governing these programs. We asked benefits counselors what are the most important traps to avoid, the most important things people may need to know as "first aid" to preserve their access to benefits, even before they get to an expert adviser.

Audrey K. Doughty, executive director of AIDS Benefits Counselors, a new San Francisco organization which specializes in Social Security and employee benefits and advises other organizations as well as individual clients, suggests, "To be a friend to a person who has tested HIV positive, encourage him or her to start early on financial planning.

"Many have panicked after testing HIV positive (and especially after an AIDS or ARC diagnosis), then quit their jobs, losing benefits for which they have worked and to which they are entitled. Others lose their benefits by staying on the job longer than they are physically able and getting fired for poor performance.

"You must familiarize yourself with the provisions of your benefits package. Obtain a copy of your company's actual contract with their insurance firm. Frequently a shorter, simplified version is handed to employees, and it may not give you the precise and complete information you need."

Diana Kuderna, a benefits counselor in Alameda County, CA (near San Francisco) and chair of the East Bay AIDS Response Organization, makes the same point and adds other suggestions:

"If your illness is beginning to interfere with your work, rather than leave or allow yourself to be terminated from a job that includes benefits, you and your doctor need to consider a disability leave, as benefits can be lost otherwise. In order to retain access to extended health-care benefits, and short or long term disability plans, you must be employed when deemed disabled."

Ms. Kuderna added that many people also lose benefits by going part-time without checking on requirements or negotiating retention of benefits.

A physician can declare a patient disabled entirely, or only for full-time work but still able to work part time. The employer does not need to know that disability is being considered until after the determination has been made. If you are found to be disabled only for full-time work, then if you continue to work part time, you may still receive up to 100 percent of State disability income (in California at least), in addition to your part time earnings, providing that the total does not exceed your income before applying for disability.

There are many more important points to know, for example:

* In most (but not all) jobs, if you leave the job for any reason, you can keep the medical insurance for up to 18 months by paying premiums yourself. However, you must make arrangements to do so within the allowed time - and pay all the premiums when due. (This right to extend a health-insurance policy by paying the premiums oneself is provided by a Federal law, known as COBRA. Unfortunately, the insurance period expires six months before the two-year disability requirement for Medicare, leaving a six-month gap in coverage. This gap needs to be fixed by legislation.)

A few employers will continue to pay premiums for about six months after an employee leaves. The employee must begin paying when the employer stops, in order to maintain the health benefits. Usually, however, the employee should apply for COBRA immediately.

Businesses of less than 20 employees are not required to offer the COBRA extension of benefits.

* If you qualify as disabled under Social Security, you may then qualify under either of two programs for disability income:

SSDI (Social Security Disability Income, sometimes called "SSA") does not require low income and assets. But you must have paid into the system for five of the last ten years (less for those age 24 and under). And no benefits will be paid until after five months of disability.

SSI (Supplemental Security Income) requires low income and assets, as well as disability. But you do not need to have paid into the system to qualify. And there is no five-month waiting period. Benefits usually take a couple of months to kick in, but then they are retroactive to the initial by-phone benefits request - your "protective filing date." (SSDI is not retroactive.)

* Persons with CDC-defined AIDS are usually presumed by Social Security to be disabled. But persons with ARC are often denied disability, even if they are equally or even more disabled than many persons with AIDS. AIDS Benefits Counselors has an excellent record in appealing these denials and getting them reversed. Careful record keeping (including very detailed descriptions from physicians) is often required.

* There are other health-care and disability-income possibilities, including Medicaid (Medi-Cal in Calif.), and state disability insurance. Medicaid may be valuable even for persons who have private insurance. However, the program varies greatly from state to state.

Ms. Kuderna described some advantages of Medi-Cal (California's Medicaid program) even for those who have other insurance:

"While essential for the uninsured, the program is also useful as a supplement to insurance. It will pay for care not covered in your policy - dentistry, chiropractic care, mental health services, drug detox, supplies ordered by a doctor, and nursing home care. Medi-Cal allows you to use health-care providers - those that accept Medi-Cal as partial or full payment - outside of your HMO (Health Maintenance Organization) provider list. If your policy has deductible amounts and percentages that are not payable, Medi-Cal can cover them. Some care providers and pharmacies expect you to pay now and bill insurance yourself. Medi-Cal can be used to avoid the difficult cash outlays. If your condition makes it difficult for you to take public transportation, cabs to medical appointments can be paid for by Medi-Cal. Note that there is no cash reimbursement, only 'compensatory stickers.'"

* Do not overlook miscellaneous programs available in some areas, such as private or religious AIDS emergency funds, free or low-cost food programs, greatly reduced fares on public transit for persons with disabilities, and others.

* Ms. Kuderna emphasized some practical hints which could be overlooked:

(1) In California at least, In-Home Support Services can be used to pay for anyone of your choosing, including a lover, spouse, or family member, to help with home chores up to 283 hours of help per month at minimum wage. You must require chore service in your home (the number of hours is determined by a home visit) and be eligible for SSI, except that your income can be somewhat higher. Those paid to do the work can have any income. Other states may have similar programs.

This program may also enable you to qualify for Medi-Cal even if your income would otherwise be too high. By an arrangement with your chore helper not to bill for the first certain number of hours per month (i.e. to pay for them yourself), you can reduce your income for Medi-Cal eligibility purposes.

(2) Payment for cost of experimental treatments is often a problem. But for meeting SSI income limits, you should be able to deduct the cost of experimental treatment supervised by a physician from earned income. (We do not know about states other than California.)

(3) Ms. Kuderna encourages people to consider State disability insurance. One fact the disability Office may not tell you is that you can collect disability income for more than one year maximum. If your physician releases you to go back to work for more than a 14 day period (even if you do not actually find work in that time) and then re-imposes restrictions, a new claim can begin. (Again, we do not know how eligibility varies in different states.)

WHERE TO GET HELP AND ADVICE

* Check with your local AIDS service organization. If you do not know what is available in your locality, start by calling the National AIDS Hotline, 800/342-AIDS. (This excellent referral service has up to 40 information specialists available 24 hours a day, so usually there is no wait to get through. It has one of the largest AIDS referral databases in the country. Unfortunately, this hotline is not well known.)

Spanish speakers can call the National AIDS Hotline at 800/344-SIDA, to reach a Spanish-speaking information specialist.

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BENEFITS (Cont'd)

* As an example of the kinds of assistance which may be available from local AIDS service organizations, the San Francisco AIDS Foundation has weekly benefits workshops for persons with AIDS or ARC, both morning and evening sessions. The workshop includes all Federal, State, and local disability benefits, employer-sponsored benefits, and insurance. It also includes other social services available through the Foundation, and elsewhere in San Francisco.

To register for the workshops, call the San Francisco AIDS Foundation, (415) 864-5855, and ask to speak to the on-duty social worker. Clients can also meet individually with a social worker for a benefits review.

The Foundation also sponsors a twice-monthly benefits seminar for Federal employees with AIDS or ARC. To register call the on-duty social worker, 864-5855.

* Chris Alexander, a benefits expert at the Foundation, emphasizes how much can be done early - while one is HIV-positive, before receiving an AIDS or ARC diagnosis - to preserve one's access to medical care, disability income, and insurance.

* Persons with ARC have special difficulty qualifying for Social Security disability. The San Francisco AIDS Foundation has a program for them, using a team of volunteers to explain what is required and how persons can improve their chances of qualifying. The team follows up with clients, and with the Social Security Administration. It cannot guarantee acceptance, but it can guarantee that Social Security has a complete picture of a client's background.

* On ARC disability, Diana Kuderna adds, "Documentation submitted to assist in determining the severity and probable duration of disability can include reports written by anyone closely familiar with your daily routine. Several such descriptions of limitation of function resulting from your illness can help, including what you can and cannot do as a result of fatigue, pain, mental changes, nausea, diarrhea, confusion, drug side effects, sleep interruptions, weakness, depression, rashes, anxiety or forgetfulness."

* Persons with ARC can also obtain a 95 page manual, Guide for Social Security Disability Insurance Claims for HIV Disease (AIDS and ARC), by Patrick James, a founder of AIDS Benefits Counselors. In San Francisco, New York, and Los Angeles the book is available at A Different Light Bookstore; it can be ordered from AIDS Benefits Counselors, 415/673-3780. This book includes forms and sample medical narratives which show the level of detail with which physicians should document ARC disabilities.

It includes a checklist to be used by persons with ARC, and their friends, family, and physicians, which has been very helpful in documenting disability. It tells that sections must be changed for California users outside the San Francisco Bay Area, or by those outside of California. From AIDS Benefits Counselors the book costs \$25 (plus \$5 handling) for agencies, but is free to persons with AIDS or ARC who cannot afford it.

* Diana Kuderna has prepared a ten-page writeup "AIDS/ARC Benefits Counseling in Alameda County." This article, full of detailed information about eligibility criteria and other aspects of many disability, insurance, and other benefits programs, was written primarily for training benefits counselors. Applicants may also find it useful, however; and even persons outside of Alameda County or outside of California may find valuable hints and ideas in the article, although the details will differ. You can obtain a copy by sending a self-addressed stamped envelope (with two ounces of postage) to: Diana Kuderna, 871-1/2 52nd Street, Oakland, CA 94608.

* We spoke with a hospital intake worker, who urged people to have medical insurance information with them (such as the name of their insurance company or HMO, and policy numbers) in case they need to be admitted to a hospital. Many plans require pre-authorization in order to reimburse for certain procedures (or notification within a certain time afterwards, in case of emergency). Sometimes people do not know the name of their company, and while they are in the hospital there may be no one at home or at work to find out.

* Chris Alexander emphasized the importance of becoming familiar with your local AIDS service organization, and of finding out what is available in your area (including emergency funds, money to pay certain bills, and county benefits such as food stamps or general assistance which vary from county to county). Insurance and benefits problems can be overwhelming when one is dealing with everything else about an AIDS or ARC diagnosis, so be aware of how an AIDS service organization can help, for example by assistance in filing applications, or by explaining the paperwork requirements. People do not need to go it alone.

For Information on how to Subscribe to ALERT, please contact: ALERT, c/o UFMCC, 5300 Santa Monica Blvd., Suite 304, Los Angeles, CA 90029; 213/464-5100.

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